

The lived experience of mental health service users in a UK community rehabilitation scheme

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Aims: There is a paucity of research on the lived experience of mental health service users in community rehabilitation services. This exploratory study researched this phenomenon within one UK community rehabilitation scheme.

Methods: A non-experimental phenomenological design and analysis of semi-structured interviews enabled an exploratory description of the phenomenon. Use of this design was based on policy recommendations and gaps in the literature on the lived experience of users.

Findings: Interpretative phenomenological analysis of data yielded five overarching themes not previously reported: belief about mental illness; the value of independence; community rehabilitation scheme accommodation/peer relationships; adjusting to a community setting; and feeling involved in care; all of which emerged from 64 sub-themes related to the phenomenon.

Conclusions: The study revealed shared and unique experiences and highlighted how being cared for within a community mental health rehabilitation service involved users carefully/logically weighing up gains/disadvantages; such as being provided with accommodation/financial benefits together with feeling 'labelled'/coping with a potentially stigmatising diagnosis. The study yielded rich and varied data as individual experiences are posited as differing according to users' own perceptions, experiences and social context. Implications are discussed for professionals working in community mental health rehabilitation settings.

Key words: ■ lived experience ■ community rehabilitation ■ mental health ■ schizophrenia

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United Kingdom (UK) mental health policy continues to highlight a positive role both for community-based settings and the voices of service users in the fashioning of service delivery (Department of Health, 1999; 2001; Goodwin, 1993). Current services are commissioned to provide care within less socially stigmatising settings compared to those of previous eras (Goodwin, 1993). Services such as the Community Rehabilitation Scheme (CRS) currently try to combine psychiatric/social care to enable user independence. CRS is commissioned by the National Health Service (NHS) from Creative Support, an independent sector organization working under the auspices of the UK's National Care Standards Commission (Creative Support, 1998). The CRS employs qualified mental health professionals and support workers to provide packages of community-based rehabilitative care that combine housing provision, statutory benefits and tenancy agreements.

AIMS

The concept of community rehabilitation has gathered socio-political impetus over the years as mental health services have evolved. The authors, who have experience in various mental health settings, were keen to explore this area and conducted an exploratory study to highlight and understand the lived experiences of service users within one community CRS in the UK. The findings have implications for practitioners working in similar settings.

BACKGROUND

The inner city CRS explored in this study was commissioned to provide care packages for 21 male service users with schizophrenia diagnoses aged between 18–65, living in shared/supported accommodation. Users of the scheme are supported for

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between 2–4 years before moving on to other settings. CRS represents an innovative context not replicated by other services; the main goal of the care team is to promote independence through development of users' personal/domestic life skills

A literature search was undertaken to identify themes relevant to CRS users and to identify appropriate research methods. Studies were included that met the following criteria: 1) used qualitative methods; and 2) focused on the lived experience of mental health service users in community rehabilitation settings. Databases searched included: Cumulative Index to Nursing and Allied Health Literature, Psychiatric Information, and Medline. Key search terms included: 'Phenomenology', 'Mental Health', 'User Experience', 'Lived Experience', 'Schizophrenia' and 'Community Rehabilitation'. The search identified a total of 42 studies which were of relevance to services users in receipt of schizophrenia diagnoses. The relevant themes—that of user experiences/involvement, medication and occupation/employment—are summarized below.

User experience and involvement

UK policy highlights the importance of user experiences (Department of Health, 1999; 2001) yet few studies have focused on user experiences within community-based mental health rehabilitation, possibly a result of their dispersed locations (e.g. Canvin et al, 2002). Some studies reflected users' knowledge of community settings (e.g. Goodwin, 1993; Rose, 2001; Canvin et al, 2002; Carrick et al, 2004) and revealed that users are:

- Insufficiently involved in service implementation/management (Crawford, 2001)
- Can be poorly informed about medication (Crawford, 2001)
- May have care programmes lacking any objectives (Canvin et al, 2002)
- May fail to receive copies of their own care plans (Canvin et al, 2002).

User involvement is associated with service effectiveness (Blenkiron, 1998; Pilgrim and Rogers, 1999) and incorporation of users as experts in their own illness is seen as useful for service delivery, promoting person-centeredness and social inclusivity (Tait and Lester, 2005). The latter term conveys ambiguity by meaning both better integration of users within society without marginalization (Tait and Lester, 2005) and better societal integration of those stigmatized with psychiatric labels (Simpson and House, 2002). Initiatives in which users act as employees, researchers and/or trainers (Simpson and House, 2002) are also seen as therapeutic (Crawford, 2001). Similarly the term 'service user' may indicate a pathologized identity while also pointing to identities/roles such as 'consumer', 'provider' and 'survivor' (Tait and Lester,

2005); although Sharma et al (2000) reported that more mental health users prefer the label 'patient' to that of 'client', 'survivor' or 'consumer'.

Medication

Medication is shown to influence users' wellbeing as a function of:

- Managing treatment, which includes involvement, control and relationship with health professionals
- Understanding situations, which includes insight and beliefs about illness
- Evaluating treatment, which include positive/negative effects of various treatment modalities (Carrick et al, 2004).

Occupation and employment

Supported occupational job schemes that offer users assistance are reportedly more effective than forms of paid employment, unlike prevocational training (Crowther et al, 2001). Legal restrictions apply to the total number of paid hours users can work before benefit is reduced (Disability Alliance, 2007). Therefore, it may not be viable for all users to sustain paid employment. Overcoming such institutionalized stigmatization and/or discrimination has always been part of official policy, yet debate exists over the most effective measures to achieve it (Green et al, 2003). For example, users are known to disapprove of traditional mental health campaigns that represent users as inherently vulnerable so perpetuating stereotypes about users' so-called vulnerability (Green et al, 2003).

Approaches to research

Few existing studies used phenomenological approaches. Olson (2002), a psychiatrically diagnosed mental health nurse, analysed his own experience as a service user. He reported experiencing shame, medication, confusion, labelling and stigma; all of which led him subsequently to view diagnoses as crudely crafted hypotheses formulated by caring, yet distracted, professionals (Olson, 2002: p438). Olson (2002) showed that knowledge/real world action(s) emerge(s) from the experience of being a user; implying that adoption of a phenomenological approach had potential to render such phenomena in their true, unbiased and essential forms (Collaizzi, 1978). The literature review also showed that semi-structured interviews were conducive to a phenomenological approach by enabling data creation in which respondents draw on their own world views/language (Collaizzi, 1978). As the literature was also found to under-report personal experiences of service users in community-based rehabilitation schemes (Olson, 2002), so the aims of this study were formulated to identify such experiences and assess their relevance to rehabilitation practice.

METHODS

Ethical considerations

Both university and NHS research ethics/research and development approval was applied for and duly granted. All potential participants were mailed an information sheet. If they were interested, or had further questions, they could contact the researcher by telephone. A meeting was then arranged in which they could ask further questions and, if desired they could enrol in the study by signing consent forms. Pseudonyms were used to anonymise all verbatim quotes and interview transcripts could not be shared with other CRS staff.

Sampling

Formal NHS/University ethics approval required the prospective participants to be: 1) in the care of CRS; 2) living in the community either alone/sharing but not in-patients; and 3) able to participate in an English language interview. Based on these sampling criteria, 15 services users (from a total of 21) were identified as potential respondents by meeting the criteria. Of these 15, ten expressed an interest; with five others stating that they did not wish to participate. Before the interviews began, three of the ten participants who were originally interested withdrew their participation prior to enrolment because they felt that they did not want to be involved in research.

Data collection

All interviews were semi-structured (Hunt and Smith, 2004) and tape-recorded in participants' homes. The interviewer was a staff member of the CRS and known to the participants; it was felt that this familiarity would help participants to talk candidly about their personal feelings/experiences. Each interview consisted of open, non-leading questions and probes with minimum direction. All participants were initially asked the following question about their experience of CRS as a starting point for narration of personal experience: 'What is it like being part of the CRS?' The following open-ended probes were used to elicit meaning and clarify incomplete/ambiguous responses (Babbie, 1992):

- 'Can you elaborate?'
- 'Earlier you mentioned ____'
- 'How did that make you feel?'
- 'Can you give me examples of what you mean?'
- 'Please continue'
- 'What did you mean by ____?'
- 'How did that experience affect you?'
- 'What does/did that mean to you?'
- 'Go on'

The interviewer used personal reflection/attentive listening with eye-to-eye contact and forward leaning/head nodding to demonstrate interest and to encour-

age participants with their narration (Kimble, 1990). Interview length was determined by each participant.

Data analysis

Phenomenological analysis preserves each unique lived experience of the phenomenon and enables understanding of meaning (Banonis, 1989: p37). Therefore, analysis began during data collection with the lead researcher actively listening, clarifying, reflecting and intuiting (Chambers, 1998). All interviews verbatim were transcribed manually. For purposes of credibility and trustworthiness all research participants were re-approached during analysis to elicit their feedback on the emerging themes/narratives relating to their transcript. The supervising researcher [KC] provided ongoing critical appraisal of data transcription, coding, analysis and the emerging thematic findings, thereby enhancing the trustworthiness of the data analysis (Smith, 2007).

Analysis was underpinned by Smith's (1996) idiographic case-study approach for Interpretative Phenomenological Analysis (IPA). IPA is a bottom-up inductive approach that attempts to understand how individuals make sense of/perceive experiences. It simultaneously gives the researcher a privileged insight into the subjective world (Smith, 2004). This approach requires the researcher to continually engage in a process of reflexive bracketing so to cast aside their personal assumptions/biases and uncover the essence of the phenomenon under scrutiny (Finlay, 2003). The researcher works collaboratively with research participants using the latter's interpretations for interpreting data. The researcher effectively becomes a phenomenological 'insider' through immersion in the private perceptual world of the research participant (Smith, 2004). Through collaboration, reflexivity and interpretation, the elements of the phenomenon in question are gradually revealed. IPA enables the identification of shared experiences and/or unique themes within small samples of respondents (Smith, 1996; Fade, 2004). Each transcript was read thoroughly several times and coded according to the themes as they were abstracted (Smith, 1996; Fade 2004). Themes from one transcript informed the analysis of each succeeding transcript (Smith, 1996; Fade, 2004). The abstracted themes were relationally clustered enabling the creation of 'overarching'—cf 'super-ordinate' (Smith, 1996)—themes, which reflect broad commonalities underpinning the discrete 'sub-themes'—cf 'subordinate' (Smith, 1996).

Hermeneutic reflection (Finlay, 2003) was adopted during analysis to enable the coder to serially re-engage with the transcripts to re-evaluate themes/interpretations in a cyclical and repetitive manner, with the aim of uncovering multiple layers of the phenomenon (Husserl, 1962). The process of reflexivity

required the researchers to be aware of the manner in which their involvement contributes to the construction of the data in the framework of understandings (hermeneutic). This framework is developed by the research participants, who are viewed as knowledgeable actors (Giddens, 1982; 1984). It is accepted that excluding bias is not fully achievable in qualitative research (Finlay, 2003). Thus, bracketing/reflexivity were ongoing as the researchers critically interpreted participants data to analyse how a double hermeneutic pertains. In this approach, participants' lived experiences are shaped by their own understandings, and this in turn helps to shape their own real world practices/actions as participants; so reflexively constitute their lived experience—the object of study for the researchers (Giddens, 1982; 1984). Such critical awareness of the operation of a double hermeneutics enhanced the validity of the analytic findings, as the researchers engaged with the meaningful social world formed in the participants' language, and reflected in the researchers' own language (Giddens 1984: p374).

FINDINGS

The mean age of the seven participants was 39 years (standard deviation (SD)±10 years; range 29 years). Participants had been with CRS a mean of 3.9 years (SD ±3.3 years; range 8.7 years). Five overarching themes and 64 sub-themes emerged (*Table 1*). All participants ($n=7$) agreed with the researcher's labelling of emergent themes based on the transcribed interviews. The phenomenological approach used in this study highlighted elements of the lived experience that constitutes being cared for by a community rehabilitation scheme. Although all the participants were in receipt of the same service, IPA illustrated that individual participant experiences were rich and varied, as well as highlighting shared elements. The next sections, in turn, describe each of the overarching themes together with their respective sub-themes.

Am I mentally ill?

Some participants expressed ambivalence and critique of their diagnosis, which appeared to influence their perceived identity. The concept of identity was central to participants' lived experience; it predisposed their attitudes, views and experiences and influenced the nature/essence of subsequent themes. Several participants articulated both non-belief in having mental illness and in treatment efficacy:

'...I don't believe I've got a mental illness it's more physiological with me. It's never been looked into though...' Lance

'I don't have mental illness, the voices are real...' Bob

Other participants said they thought they were experiencing mental illness and that their psycho-

tropic medication worked for them:

'...I can remember times when I've been really unwell in the past so yeah there's no doubt that I have a mental illness, I'm just glad that the medication and the support I get help me.' Lou

'I was ill for many years and didn't respond to medication, but now I respond and doing incredibly well.' Shane

Participants' articulated views on both their treatments and the nature of mental illness were mutually intertwined. Some participants who articulated non-belief about having mental illness also complied with treatment but said their treatments had no personal benefits for them:

'I've been taking medication for twenty odd years now; I don't like taking them because I don't believe they work.' Bob

'...I don't feel I need it, but I'm willing to keep going because the doctors say that I need to continue to take it for the foreseeable future, but one day I want to be medication-free.' Jim

Given the views expressed on having/not having a psychiatric diagnosis, the above admissions of compliance seemed somewhat unexpected. For example, it could be hypothesized that those articulating contests over the identity of their illnesses (and so contesting the validity of their psychiatric diagnosis) may be more likely to articulate non-compliance with medication, and vice-versa. Participants expressing the view that they were experiencing a mental illness also articulated how medication worked for them and did not express any criticism about medication:

'I was ill for many years and didn't respond to medication, but now I respond and doing incredibly well. I'm very very grateful.' Shane

'I take my own medication every night at six; I don't know what I'd do without it. It works for me....' Mike

A further sub-theme concerned the negative effects of medication:

'It makes me groggy, it makes me piss too much er, it affects me kidneys. I got a very strong metabolism me. It makes me feel a bit subdued as well after taking 400mg of clozapine at night it wipes me out it's quite heavy. It makes my mouth very dry as well. Because it wipes me out I get a good nights sleep but it sometimes feels like I've had twelve cans of cider when I wake up in the morning.' Lance

Another sub-theme—of negative hospital experiences—was not exclusively articulated by either of the above participants:

'I had bad experiences before I came to the scheme, when I was in hospital...' Jim

'The times I have been in (hospital) have been horrible.' Bob

'In my experience the hospital staff can be quite difficult and rude...the crap I went through in hospital...' Lou

The related sub-theme of 'stigmatization' emerged in connection with descriptions of tangible stigma caused by having a psychiatric diagnosis and being

treated differently by people in the community:

'...having been given a free travel pass to use on public transport that um, particularly bus drivers, when you get on and show your pass they tend to give you a condescending sneer and look down at you.' Stewart

Striving for independence

The high value of independence since joining the CRS was a theme voiced by all participants. Concerns about independence were further characterized by freedom to come and go; to undertake

Table 1.
Overarching themes and sub-themes emerging from interviews with mental health service users of the Community Rehabilitation Scheme (CRS)

Am I mentally ill?

- | | | |
|---|---------------------------------|------------------|
| ■ Beliefs about illness | ■ Beliefs about treatment | ■ Paranoia |
| ■ Medication effects | ■ Hearing voices | ■ Anxiety |
| ■ Comparison of self with others | ■ Sense of achievement | ■ Self doubt |
| ■ Acceptance of mental health diagnosis | ■ Negative hospital experiences | ■ Stigmatization |

Striving for independence

- | | | |
|--|----------------------------|--------------------------|
| ■ Independence | ■ Sense of achievement | ■ New experiences |
| ■ Decrease in alcohol/cannabis use | ■ Feeling less labelled | ■ Leading a normal life |
| ■ More trusting of people | ■ Social network | ■ Improved social skills |
| ■ Reduced independence | ■ Dependence from services | ■ Benefits |
| ■ Independence from mental health services | | |

Connecting with peers and with life

- | | | |
|---------------------------------------|---------------------------|--------------------------------|
| ■ Benefits of living with other users | ■ Living with other users | ■ Privacy |
| ■ Lack of privacy | ■ Feeling safe | ■ Feeling alone |
| ■ Competent staff | ■ Unsupportive staff | ■ Feeling paranoid about staff |

Adjusting to a new way of living

- | | | |
|---|--------------------------------------|-------------------------|
| ■ New context and/or geographical area | ■ Support from CRS staff | ■ Poor social networks |
| ■ Supportive/unsupportive relationships | ■ Good social networks | ■ Family networks |
| ■ Poor family relationships | ■ Poor relationships with doctors | ■ Poor social networks |
| ■ Collaboration | ■ Feeling socially accepted/excluded | ■ Feeling less labelled |
| ■ Expectations of CRS/CRS staff | ■ Unfulfilled service user needs | ■ Service resources |

My care, my choice?

- | | | |
|---------------------------------|----------------------------|---------------------------|
| ■ Care management | ■ Feeling involved in care | ■ Control |
| ■ Lack of control | ■ Family involvement | ■ Collaboration |
| ■ Cognitive behavioural therapy | ■ Sleep clinic | ■ Specialist care |
| ■ Supportive staff | ■ Caring staff | ■ Staff as good listeners |
| ■ Feeling safe | | |

cleaning, shopping, cooking and generally undertake self-care activities. The following excerpt summarizes the typical positive views articulated about independence:

'...one of the positive aspects of being at (CRS) is gaining a measure of independence, with regards to cleaning, shopping and getting out and about.'
Stewart

However, not all participants expressed such views:

'...I've lived by me self since the age of sixteen and looked after me self until I went into hospital and came into this scheme. I still look after me self but I now live with someone which I feel takes away a bit of my freedom...when he (house mate) goes away to his parent's over the weekend it's great I can relax then and chill out. But when he's here, at first it as all right but now it's really grinding me down at the minute, so I'm tending to spend a lot of time alone in me room...I love me independence and I'd rather be on me own.' Lou

The experience of prior high levels of independence being adversely affected by the CRS setting did not emerge from all participants. However, the lived experience of having to share accommodation with other CRS users was not always reported as overwhelmingly positive. A sub-theme of 'independence from mental health services' emerged. It is noticeable that this sub-theme referring to being liberated from mental health services only emerged from participants articulating criticism of the validity of their psychiatric diagnoses; as if they felt oppressed by mental health services. This theme expression was not found in any of the current literature:

'My aim is to get out of services...I would like to have a decent flat of me own and have more friends than I do now. Somewhere with privacy and free from services would be nice.' Lance

Connecting with peers and with life

CRS accommodation and peer relationships formed an integrated overarching theme, which was expressed by the majority of participants. As a result of having to share accommodation, most participants developed relationships with each others, and with CRS staff. Participants commonly reported these as pleasant experiences in which close relationships could develop:

'...I'm very lucky that the two people that I share the house with I've known from when I used to live at [name of road] they're two very nice people, they're

very kind and very thoughtful. They told me that they were happy it was me who was moving in to live with them. We've grown even closer together and go out together...' Stewart

Face-to-face/group interactions together with enjoying others' company and a general improvement in social life were resonant themes:

'...living and being with other patients you build life friends really.... I share with two other people here and we have formed good friendships. We all get along really well.' Shane

'...I got friends now; I didn't have friends before...' Stewart

'...I sometimes join in on some of the activities sometimes, it helps me get out and socialise with other service users.' Jim

'Since coming here I've mixed more with people and I'm more trusting also. I've got more friends too I never used to give people a chance before I made my mind up about them but now I would. So I'm a more sociable person.' Lou

'...I've known S for 12 years now, and we've lived together for four years, we're best friends, we go out together, go to the shops and go for a coffee almost everyday.' Mike

The sub-theme of 'experiencing pleasant/close relationships' was not evident in all participant interviews. Some participants felt that they did not have much in common with fellow 'house mates' so leading to them to experience loneliness:

'I must have had about three conversations with him [name of house mate] in about 8 months, he was antisocial, I may as well have been living by me self. He was no house mate. I hardly ever saw him anyway; he was always in his room sleeping. Looking back it was a bad move I only moved to [name of road] to improve my situation financially. I didn't feel connected down there and wasn't making any friends so I was glad to move back...' Lance

Some participants felt that having CRS staff present all the time encroached on their privacy and made them feel that they were under constant scrutiny. Not all participants talked about relationships with CRS staff positively:

'...I don't feel that the doctor listens to me or takes into account when I say that I don't need it...' Lance

Adjusting to a new way of living

An overarching theme of adjusting to the move away from hospital to a community setting emerged from several participants. Further sub-themes emerged relating to moving to this new social context and/or a new geographical area and the support users received from CRS staff during this adjustment process:

'...it took me a while to get used to being here. The hardest thing I had to get used to was not living in the same area I grew up, away from me mam and dad in a new area that took a while to get used to.' Jim

'I couldn't wait to move out of hospital into the community scheme. It took about three years for it to happen but I have no regrets whatsoever. I settled in very quickly, but what has really made the difference is having the support.' Lou

These remarks reveal how necessary support is to optimize adjustment when moving out of an institutional setting and into a community-based setting. However, relocation may not be without its negative aspects, such as moving away from family and other familiar social networks which have accrued over time. Related to this overarching theme were the sub-themes of 'social acceptance/exclusion':

'The neighbours are friendly and nice, they always say hello and when I moved in they came over to introduce themselves. They made me feel welcome as soon as I came here...' Bob

'...I know what it's like trying to be accepted by people in a small community, I've tried it in two or three and when they find out you have mental health problems they can turn on you and shun you.' Stewart

My care, my choice?

An overarching theme of 'feeling involved in care' emerged from those participants who felt included and viewed themselves as active members in their care management. Participants considered that they were to some degree involved in their care:

'I'm involved to quite a degree in my own care, er, joining forces with the support staff to get my er opinions and views and worries out in the open.' Stewart

'If there are any changes to my meds I am told at the review which I really appreciate. I'm very grateful for being informed at every stage of my care...' Shane

Not all participants experienced this feeling of involvement. For example, experiences of not being listened to, or being disbelieved by doctors in particular, who could disallow choice and personal control over medication decisions:

'...I don't have much of choice of where I end up. My aim is to get out of services but I don't think it will happen because the doctors don't believe me when I tell them things...Another thing I don't like is having to take the medication whether I like it or not, I don't feel that the Dr listens to me or takes into account when I say that I don't need it.' Lance

The sub-theme of feeling less labelled emerged in participants' narratives on life after joining CRS. This was poignantly expressed by one participant who described the association of psychiatric diagnosis with a particular setting:

'...I just felt labelled a schizophrenic or what ever my diagnosis is in hospital and felt I couldn't get away from it....I don't feel labelled as much here.' Jim

The lived experience of the CRS setting may not engender the same relative order of diagnostic stigma as the hospital setting. Although this feeling of involvement was a shared experience it was not common to all participants. Previous research has suggested that involving mental health service users in their care management is highly beneficial to both the individual and for service planning (Crawford, 2001), and was reflected in the participants' views :

'...I like to discuss with the doctors and nurses how I'm getting on and they always want to know how I feel to changes in my care.' Lou

'...If there are any changes to my meds I am told at the review which I really appreciate. I'm very grateful for being informed at every stage of my care...' Shane

'I'm involved to quite a degree in my own care...' Stewart

DISCUSSION

Study limitations

This exploratory study was subject to several limitations. First of all, only white males could be sampled thereby omitting the views/experiences of both women and ethnic groups. Secondly, owing to the demographic of users, only the experiences of individuals with a schizophrenia diagnosis could be sampled. Thirdly, this relatively small and

homogenous sample limited the diversity of data. Further study in this area would ideally require a larger sample of users with heterogeneous ethnicity, diagnostic labels and gender mix. However, even with these limitations the findings positively illustrate novel themes of identity work and social functioning, which have been relatively under-reported in the current literature on community mental health rehabilitation.

Identity work

On the surface it appeared that the participant group was diametrically opposed in their views/beliefs, in the overarching theme of 'Am I mentally ill?', for example. However, closer examination of the data as a whole revealed complex layers of ambivalence and contest within participants' responses. Some participants openly contested whether they were experiencing mental illnesses, while others asserted the validity of their diagnoses and articulated compliance with prescribed treatment. The latter also reported how medication was beneficial, how they felt involved in the management/delivery of their rehabilitative care and their satisfaction with the status quo. Those participants openly contesting their diagnoses also thought that psychotropic medication was not always beneficial. Yet they also articulated their compliance with medical prescription while simultaneously articulating their dislike of taking psychotropic medication. The genesis of such viewpoints cannot be attributed solely to prior negative in-patient experiences, as these were not exclusively experienced by those contesting their diagnoses. These views reflect meanings that individuals attribute to their experiences which differ to those attributed by medical authorities (Barker and Buchanan-Barker, 2005); thus helping shape their lived experience in the CRS setting (Giddens, 1982; 1984).

These findings on participants' views on mental illness within the CRS setting warrant further research. Aspects of the findings resonate with those of Gove (2004) and Thornhill et al (2004). For example, lay people previously hospitalized within a 'mental illness career' (from admission to discharge an individual takes on the identity of a patient and progresses through different levels of independent community living) attempt to re-establish a less socially stigmatized identity by retrospective assessment of their functioning over time; this has been conceived of as a recovery approach (Gove 2004, Thornhill et al, 2004). This may involve 'identity work' whereby the individual draws on lay distinctions between concepts of 'nervous breakdown' and 'mental illness' to develop their own interpretive mean-

ings (Ridgeway, 2001) for the complexity of their experience inside of psychiatric services, such as 'nervous breakdown' (Gove, 2004: p369) or resisting the identity of a 'chronic psychiatric patient' (Thornhill et al, p188). Although the study did not aim to focus on the concept of recovery per se, findings from within the CRS setting do uniquely reflect similar lay 'identity work' that attempts to distance the user from the perceived stigma associated with diagnosed mental illness by movement towards developing a less stigmatized identity (Gove, 2004; Thornhill et al, 2004). This was seen, for example, by one respondent's ('Lance') attribution of the causation of their mental health problems to physiology. By articulating contests over the epistemology of diagnosis, participants could be articulating their perceived truth as well as attempting to help re-establish a less stigmatized social identity (Gove 2004, Thornhill et al, 2004).

Furthermore, the findings relating to identity also highlight the expectations placed on those who eventually become users of a CRS-type service in terms of consumption of medication inside some form of 'psychiatric career' (Karp, 1996; Aneshensel, 1999; Gove, 2004). Of further note was the participant imagining both a future time where they could be 'totally free' of health services and a social status akin to that of recovery, without need of further psychiatric intervention(s) (Thornhill et al, 2004). These findings show how users shape their lived experience (Giddens, 1982; 1984) through reflexivity about the care system, their location within it and their perspectives on recovery. These findings further echo those of Barnett (2005) about the utility of actively listening to users (Barker and Buchanan-Barker, 2005).

Social functioning

The findings both support and refute those of Trieman et al (1999), which links community care with improvements in social functioning, mental state, daily living skills and enabling what participants describe as more meaningful relationships, despite the often negative media portrayal of community care. Although some users reported improved social functioning since joining CRS (e.g. daily living/socialising; peer bonding), others also felt that their developing independence was inhibited by having shared accommodation after previously living alone. The findings also echo those of Green et al (2003) which demonstrated how users experience some form of stigmatization, as several participants reported similarly feeling labelled/stigmatized by their diagnoses and their experiences of receiving social treatment that differed to others not similarly diagnosed. This finding further points to the importance users appear

to place on the concept of identity and maintaining an awareness of how they are perceived by the society in which they live and function, a research perspective encouraged by Scheff (1999). Although the most significant theme bisecting participants' experiences was their views on mental illness/taking medication, it was noticeable that the themes of improved social skills/meaningful relationships (stemming from being in the CRS setting) emerged from all participants; a finding which also supported the particular research perspective encouraged by Scheff (1999).

CONCLUSIONS

This exploratory study has highlighted particular themes relevant to the mental health community rehabilitation setting. More critical awareness of users' lived experience, especially reflective of their viewpoints on psychiatric diagnosis and the nature of illness/recovery (Deegan, 1996) may help resist tendencies to invalidate user perspectives/hermeneutic reflections through professional suspicion/mistrust if/when users contest diagnostic systems (Thornhill et al, 2004: p184). Following on from Scheff (1999), these findings are of use for enhancing existing awareness of the broader issues surrounding user interpersonal relations and lived experience within designated community rehabilitation settings, to aid such services with identifying potential problems earlier and thus addressing users' needs. CRS-type schemes could further employ the themes that emerged to design/improve their own evaluations and care plans to ensure both more appropriate user involvement and better guidance for the implementation of suitable care packages. The findings of this exploratory study may be of additional value for informing the content of future quantitative data collection methods within community mental health rehabilitation settings. **UTR**

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KEY POINTS

- Community rehabilitation is an integral cog in the mental health service provision engine, and has gained socio-political impetus over the years.
- Exploring 'the lived experience' of mental health service users can help improve health professionals' understanding of their needs and perception of the world.
- This exploratory study researched this phenomenon within one UK community rehabilitation scheme. Interpretative phenomenological analysis of data yielded five overarching themes not previously reported.
- Findings highlight how listening to service users can lead to more effective and person-centred interventions, and how involving service users in their care management can aid service user satisfaction and recovery.

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COMMENTARIES

This article is to be commended for the aim of exploring service users' experiences of mental health services. The researchers found a dearth of this kind of research in community rehabilitation services (CRS) and so undertook a study to highlight and understand the lived experiences of people using these services.

Despite the lack of research on rehabilitation services revealed in the authors' literature search, there are many first-hand accounts of living with mental health difficulties (Adame and Knudson, 2007), and much of this research has contributed to our understanding of recovery. The authors do touch on the concept of recovery, however, this could have been developed much further in light of the feelings expressed by the respondents. This would have made a useful framework for conceptualizing their lived experience.

Recovery approaches in mental health have grown from the stories told by people who use mental health services (Deegan, 1997). Embracing recovery is a difficult and challenging process for service providers (Lloyd et al, 2008), and also perhaps for researchers who deliver services. Although we might listen to service users, it can be difficult

to hear what is being said and to act on it.

Recovery is currently a very topical issue, provoking much interest, but there are a number of different ways in which the concept is being understood and applied in practice (Lloyd et al, 2008). Although there is a consensus that the word 'recovery' when applied to mental illness came from the service user movement (Davidson, 2005), there is also an argument—interestingly based on service user accounts—that the ownership should remain with the service user and that this concept provides an alternative to mainstream concepts of clinical recovery (Adame and Knudson, 2007). This view of recovery challenges an oppressive system that uses detention and medication, and incorporates elements of radical psychiatry (Casey, 2008). Now that mental health services are absorbing the concept of recovery into everyday practice and weaving it together with other concepts, such as clinical recovery (Secker et al, 2002), there is a danger that we are losing the spirit of recovery as originally conceived by service users.

There is a clear narrative in this article on negative hospital services and feeling oppressed by the system, but what is being done

about it? Why is 'Bob' still taking his medication if he feels so unhappy about it? The use of language reflects how well we are hearing and understanding. The authors describe their research as exploring the experience of 'being cared for' by CRS. We must critically examine what could be seen as a paternalistic attitude and notice when caring becomes a limitation on people's lives and the choices they make. It is interesting that one of the respondents reported feeling grateful that he was kept informed about decisions made about his treatment plan; this is a long way from collaborative care.

It is important to be reflective on what is driving practice and understand the philosophy of recovery. We should listen carefully to what service users are saying and not ignore those voices that do not fit with the systems and services that we currently provide. If 'Bob' was a service user you were working with and he stopped taking his medication, what would your immediate response be? Reflect on your reaction carefully.

This commentary does not aim to criticize the CRS where this study took place; it is fully recognized that the study setting is not a recovery-led service. The article has, however,

provoked many questions for me and hopefully others. It has therefore made a useful contribution to the debate about how mental health services can deliver humane and positive support for service users.

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Research on the lived experience of health-care service users is of great importance, and this article is an interesting contribution to the knowledge base within mental health community rehabilitation. The perspective of people receiving services is needed to help develop the quality of services, and to make us reflect on how we can best meet the needs of users, especially in community-based settings.

As the authors point out, limited knowledge exists on users' lived experiences in this area, which makes an explorative, bottom-up approach suitable. Their findings will add to the work done by researchers at Boston University (Spaniol et al, 2002) and by Sells et al (2006), among others, who have contributed extensively to the knowledge base on users' experience of recovery from severe mental illness. This growing knowledge base can help us plan recovery-oriented services.

The qualitative research approach taken in this study was appropriate to gain an in-depth understanding of people's experiences of a particular

phenomenon. By using an exploratory and phenomenological approach, the authors identify five major themes of importance for users while being cared for in a community rehabilitation scheme in England. The located themes have essential value and seem applicable across cultures, thus will be informative for practitioners and researchers in mental health worldwide. Despite the methodological limitations mentioned by the authors, the themes identified can give us a deeper understanding of how users perceive community services, and make us understand some of the challenges they face in this context.

Some of the findings, particularly in relation to the benefits of being involved in care, have been supported by other research. Although evidence is sparse, user participation and involvement have been shown to be important factors in furthering the development of social skills, service management (Valentine, et al, 2003) and in preventing helplessness (Greenall, 2006).

However, the claim by the authors that the findings can

help to ensure appropriate user involvement is not an easy one to make, as several studies have located barriers among professionals, such as negative attitudes and views on the user's capability to make choices and to be involved in care planning (Anthony and Crawford, 2000; Goodwinn and Happel, 2006; Greenall, 2006). User involvement and listening to the voice of the users seems to be a difficult goal to achieve, despite the good intentions highlighted in mental health policies. Further research on this paradoxical topic is needed to deepen our understanding and help clarify the complexity of practice.

From the findings reported by the authors on differing personal experiences according to perception, experiences and social context, it is clear that we still need to extend our understanding of how users experience everyday life while participating in rehabilitation. In particular, the findings from this study call for further investigation into barriers to user involvement and experiences of stigmatization. The themes located by the authors

may serve as a guide for this much needed research.

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